V. Principles and Future Vision

The Commission has

established a set of guiding principles that can serve as the basic framework for designing a future comprehensive system of services and supports to individuals with a developmental disability in Connecticut. These principles reflect best practices around the country and are fully consistent with the wishes and desires of the vast majority of consumers and families who informed the Commission's work.

As noted in the preamble to the principles, "Disability is a natural part of the human experience that does not diminish the rights of people with developmental disabilities to live independently, to exert choice and control over their lives, and to fully participate in and contribute to their communities, through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of Connecticut."

The guiding principles help create a vision of what the future could look like, and dictate that a redesigned system of support for people with developmental disabilities should:

Each major principle is associated with a series of images that help illustrate desired outcomes for the person and the future system.

1. Focus on the PERSON and FAMILY.

- a. Personal Choice and Controlindividuals, with the support of their family and others they choose, make decisions about what they need and how, within available resources, their supports can be best delivered. Planning focuses on their unique strengths, needs and preferences. They are able to select, and where desired, manage their own services and funding.
- b. Consumer Driven The system encourages and supports the active leadership of consumers, family members, and advocates in shaping public policy associated with disabilities issues.
- c. Family Focus When the individual lives at home with his or her family, services are made available to support and strengthen the family unit.

2. Based on PARTNERSHIP and COLLABORATION.

- a. Coordinated Services Services and supports are linked together and serve to compliment one another to provide a comprehensive program of individual support. Active service coordination is available to all consumers who desire assistance.
- b. Shared Responsibility Broad partnerships are developed among consumers, family members, public agencies and private providers. Public policy encourages active individual and family participation in providing direct and financial support. Individuals receive resources from a variety of sources (personal, insurance, civic, government).
- c. Collaboration Partners work together to establish consistent policies and systems to support people with developmental disabilities. Administrative structures are present to help coordinate and promote collaboration.

3. EASY TO ACCESS and

SIMPLE to use.

- a. Accessible Services and supports are available throughout the state and without unreasonable waiting periods. Needed services are affordable.
- b. Simple to Use The system is easy to understand and has common-sense rules and procedures. There is a single point of entry and ready assistance from a service coordinator.
- c. Flexible The system recognizes that the needs of individuals and families change. It allows for modifications to personal plans and adapts rules to the unique needs of different people.

4. COMPREHENSIVE and based on QUALITY STANDARDS.

- a. Comprehensive A broad array of services and supports are available to individuals and families that address respite, parent support, residential, employment, behavioral health, specialized medical, transportation, leisure, and adaptive technology needs.
- b. Quality Standards Services and supports meet established safety and quality standards and are monitored on an ongoing basis that is well coordinated between regulatory agencies.
- c. Best Practices Services reflect the most current practice standards. Where appropriate, they are based on empirical evidence of effectiveness and change as new research findings point to better approaches.
- d. Accountable State agencies and service providers are accountable for providing the most effective and efficient services and supports. Consumers, families, providers, and state agencies recognize their responsibility to taxpayers and use resources in the most cost-effective fashion possible.

5. Be COMMUNITY BASED.

- a. Full Partnership of
 Communities. Cities, towns, and local communities are full partners with federal and state government, and with private agencies in providing resources and support. They promote full inclusion and share in the responsibility to assure needed services are available for their citizens.
- b. Local Access to Supports A community base of supports, including natural and informal resources, is available across Connecticut. Needed services are available within the individual's community of choice. People with

- developmental disabilities do not have to travel far to access the services they require.
- c. Active Community

 Participation Towns and cities are enriched by full and active participation in community activities by individuals with disabilities and their families.

 Members of the community respect and value their neighbors with disabilities, and have ample opportunity to become involved and enhance their lives.

Develop a COMPETENT WORKFORCE.

- a. Available There is an adequate workforce available to meet service and support needs. Consumers and families do not have to wait for personal assistance or to purchase supports from providers because of a shortage of qualified staff.
- b. Skilled Workforce *Individuals* who provide support are acknowledged to be the most valuable resources in the service delivery system and are treated with respect. They are well trained and skilled. A comprehensive system of personnel development is present so that professionals and direct service staff in the schools, private provider community, independent practice, and at public agencies are competent to provide the most up-to--date services for persons with varying and unique needs.
- c. Culturally Diverse The workforce is sufficiently diverse that it reflects the cultural, ethnic, and language characteristics of the people they support. All members of the system understand, respect and value the importance of diversity. As a result, all services and supports are provided in a culturally competent manner.
- d. Respectful *All persons who provide support respect and value*

individuals with disabilities. They are knowledgeable about human and legal rights. Individuals with developmental disabilities are free from abuse, exploitation, and neglect.

THE GUIDING PRINCIPLES STRESS

- Central role of INDIVIDUALS & FAMILIES
- Need for PARTNERSHIP & COLLABORATION
- Creation of a SIMPLE & EASY TO USE system
- Services that reflect QUALITY and are COMPREHENSIVE in nature
- Working in partnership with local COMMUNITIES
- Active development of & support for EMPLOYEES

VI. Consumer & Family Perspective

The Individuals and Family Supports and Services Committee conducted **an extensive study**. This workgroup focused on answering three important questions:

- What services and supports do individuals with developmental disabilities – and their families – need?
- 2. What are the current experiences of individuals and families with access to services, payment for services, and barriers to actual receipt of critical services?
- 3. What do individuals and families believe are the best ways to organize, coordinate, and deliver needed services?

Committee members used *two methods* to answer these questions. First, they designed and distributed 8,000 *surveys*, estimated to have reached 6,500 people. Survey distribution was accomplished with the assistance of 31 advocacy organizations throughout the state. Second, the committee conducted 13 focus groups. These *focus groups* were

organized to assure that the voices of both adults and the parents of children with developmental disabilities were heard. The 67 participants represented 39 different cities and towns.

Committee members then analyzed and synthesized the results of both the survey and focus groups in order to answer the questions listed above and identify the respondents' most important concerns, needs, and desires. A full copy of the committee report is included in Appendix D.

Survey Respondents

Nearly 800 individuals, living in 182 different zip codes, returned the surveys. Overall, 60% of the survey returns represented the expressed needs of children and youth 17 years of age and younger and 40% represented expressed needs of adults with disabilities who were 18 years of age and older.

Slightly more than 60% of all individuals represented in the total survey sample live in their family home

or their own home or apartment without additional supports. An additional, 32% of individuals are living in their family home or their own home or apartment with additional supports. In contrast, 4% of individuals in this sample live in group homes, nursing facilities, or specialized institutions.

As would be expected, the overwhelming majority of children in this sample are living with their families. Less than 1% of these children are living in a group home or specialized facility. Approximately 20% of adults in the sample are living in their family home without support and another 27% of adults are living in their family home with support. Nearly 30% of adults in this sample live in their own homes or apartments without support and another 19% live in their own home with some type of support. Only 9% of this sample of adults are living in nursing facilities, group homes, or specialized institutions.

The presence of multiple disabilities appears to be a very common experience for individuals in this sample. In fact, 521 of all individuals

were diagnosed with at least two disabilities, 317 had three disabilities, 188 had four disabilities, and 111 people identified five or more disabilities.

Table 2 summarizes the types of disabilities reported by survey respondents. Given that eligibility for most of Connecticut's state funded services is based on specific diagnostic criteria, the presence of multiple disabilities likely compounds problems associated with access to existing services. In other words, the presence of a particular disability could in fact exclude individuals from access to services.

Table 2. Self-reported Diagnoses of Survey Respondents

But vey Respondents	
Diagnosis	<u>n</u>
Acquired brain injury	67
Attention deficit disorder	166
Autism spectrum disorder	256
Asperger syndrome	98
Cerebral palsy	63
Epilepsy	108
Health impairment	72
Hearing impairment	38
Learning disability	248
Mental retardation	19
Muscular dystrophy	14
Neurological impairment	156
Orthopedic impairment	50
Pervasive developmental disorder	172
Social/emotional disorder	89
Speech impairment	86
Spina bifida	6
Tourette's syndrome	6
Visual impairment	45
Other	155

Focus Group Participants

Focus group participants included 30 individuals with a disability. The remaining 37 participants were family members, who are primarily parents of persons with disabilities. The majority of focus group participants (n = 44) were from suburban settings. Nineteen

participants represented urban settings and rural areas were under-represented with only four participants.

Focus group participants, like survey respondents, often had or represented people with multiple disabilities and diagnoses. The most common disabilities among these participants included learning disability, attention deficit disorder, autism spectrum disorder, and cerebral palsy.

Findings Across Age Groupings

As they analyzed the survey and focus group data, committee members found that there were marked differences among three distinct age groupings. As might be expected, parents of children and youth birth through 17 years of age expressed different service needs than did individuals or families representing the sample of adults 18 years of age and older. The expressed needs of young adults in transition, 18 through 24 years of age, were keenly different than those of the larger adult sample.

Despite these differences, there were findings, irrespective of age, that are important to note.

- 1. A number of individuals in this sample would not be considered a person with a developmental disability based on the criteria set out in the federal definition of developmental disability. For example, 14% of survey respondents were not diagnosed with a disability prior to the age of 22. Nevertheless, they expressed critical service needs and stated that they required the support of others on a routine basis because of their disabilities.
- 2. Of the 636 individuals who were diagnosed with a disability prior to the age of 22, 38% (n = 241) indicated that they had a level of need for direct assistance or comprehensive support in three or more major life areas, and therefore, they would likely meet the federal definition of developmental disability.
- 3. With the exception of some of the most pressing needs (e.g., healthcare, service coordination, education) the number of people who indicated that they did <u>not</u> need

- a service was equal to or greater than the number of people who indicated they needed the service. Moreover, relatively few individuals indicated that they had an extensive or critical need for the more traditional and costly types of services, such as out of home residential placement or out of home respite.
- 4. While the relative priority of service needs varied as a direct function of age groupings, service coordination, recreation and leisure support, medical and health care, and community inclusion supports were expressed needs across all age groups.
- 5. In general, individuals with multiple disabilities tended to be less independent in the areas of learning, self-direction, employment, and healthcare. They were also less likely to have the information they needed to plan for and secure services. Moreover, they indicated that they neither felt welcomed by their community, nor did they have friends available to help them participate as active and respected members of their community.

- 6. Individuals with multiple disabilities indicated that they are "shifted" around from one agency to another because of agency and program specific eligibility requirements. They indicated that the service eligibility approach of "one diagnosis leading to one agency" does not work well for them.
- 7. People in the eastern section of the state and those in other rural areas were underrepresented in both the survey sample and among the focus group participants. This may be because statewide support groups do not adequately reach these individuals or because individuals do not have the same access to information and services as do people in more urban and suburban areas.

Expressed Service and Support Needs for Children

For the total sample of children from the survey, family members identified 14 of the listed services and supports as relative priorities. It is important to note that the priority ranking only reflects the

average or mean rating of need for the survey sample. The average rating does not, however, provide a full picture of the extent to which some families require a service or support. In other words, for each service or support listed, there was a significant number of families who indicated that they had an extensive need for the service, regardless of its priority ranking. Readers are therefore strongly encouraged to review the full report (Appendix D).

Figure 4 summarizes the top 14 service and support needs for children in the survey sample. Services and supports that were <u>not</u> considered priorities for these children included those associated with residential support such as housing assistance, out-of-home residential placement (e.g., group home), and out-of-home respite care, which are typically the more expensive and costly types of services provided or funded by state agencies.

Figure 4. Priority service and support needs for children and families in the survey sample.

RANK	Service or Support Area	Description	
1	Education	School-based education	
2	Assessment	Specialized evaluations and assessments	
3	Social Skills/Behavior Management	Social skills training and specialized behavior management services	
4	Life Skills Training	Education and training in basic life skills	
5	Recreation	Supports or services for leisure and recreation activities	
6	Family Counseling	Counseling services or parent/peer support networks	
7	Family Education	Special information or training for parents or caregivers	
8	Case Management	Assistance with locating and securing benefits and program services. Also called service coordination.	
9	Community Inclusion	Assistance to access /participate in community activities	
10	Medical & Health Care	Direct health care service and/or funding or subsidy	
11	Mental Health Care	Direct mental health care and/or funding or subsidy	
12	Family Financial Subsidy	Direct funds to family for purchase of necessary service or equipment	
13	In-home Respite Care	In-home caregiver to provide temporary relief/assistance	
14	Financial Assistance	Payments from government agencies directly to the individual	

Expressed Service and Support Needs for Adults

Adults with disabilities in this survey sample or their families identified relative service and support priorities that are rank-ordered in Figure 5. As with children, the need for traditional out-of-home residential placement or out-of-home respite care was not listed as a critical need by the vast majority of these adults. On the other hand, the need for financial assistance with housing and either independent living or in-home family support was identified as a need.

Employment—

"You see, it's a catch 22...you can make enough to lose your benefits, but not enough to live on . . ."

Focus Group Participant

Survey data suggest *that support*needs for adults are highly

individualized, with substantial

variation in the extent of need for
support. Therefore, "program

packages", where services are bundled
together, are not the appropriate

approach to providing services and supports to adults with disabilities.

The profile of supports and services that individuals and families in this sample desire is substantially different than those of persons currently served by

DMR. For instance, and perhaps most striking, is the fact that very few adult survey respondents (11%) indicated they had a pressing need for out of home residential placement. This is in stark contrast to well over 50% of the people served by DMR who are either already receiving an out of home residential support or who are on the DMR Waiting List after having requested residential services.

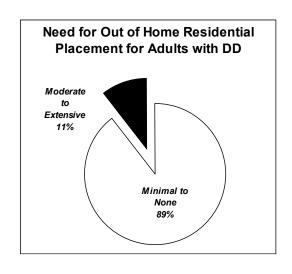


Figure 5. Priority service and support needs for adults in the survey sample.

Rank	Service or Support	Description
1	Medical & Health Care	Direct health care service and/or funding or subsidy
2	Case Management	Assistance with locating and securing benefits and program services. Also called service coordination.
3	Financial Assistance	Payments from government agencies directly to the individual
4	Recreation	Supports or services for leisure and recreation activities
5	Transportation	Individualized and adapted transportation service
6	Community Inclusion	Assistance to access /participate in community activities
7	Job Placement & Training	Assistance with finding a job and learning to do a job
8	Assistive Technology	Specialized equipment, vehicle modification, and special adaptations
9	Assessment	Specialized evaluations and assessments
10	Personal Assistant	Individual employed by the person to provide direct service/support
11	In-home Support	Independent living support or support in the family home
12	Family Financial Subsidy	Direct funds to family for purchase of necessary service or equipment
13	Family Counseling	Counseling services or parent/peer support networks
14	Housing Assistance	Subsidies, financing, modification, locator services
15	Life Skills Training	Education and training in basic life skills
16	Legal Services	Consultation and legal representation

Expressed Service and Support Needs for Young Adults in Transition

The transition from adolescence into adulthood presents special challenges for any individual. The presence of a disability and the need for continuity in supports and services only further complicates this often-tumultuous period of life.

As can be seen in Figure 6, priorities for support begin to shift closer to those of adults for individuals between 18 and 22 yrs of age. Of note, the respondents in this group indicated more extensive needs for services than either the children and youth group or the adult group. The data underscore the need for more extensive services to assist young people with developmental disabilities to become productive, independent adults.

Figure 6. Priority service and support needs for young adults in the survey sample.

Rank	Service or Support	Description	
1	Job Placement & Training	Assistance with finding a job and learning to do a job	
2	Transportation	Individualized and adapted transportation service	
3	Medical & Health Care	Direct health care service and/or funding or subsidy	
4	Recreation	Supports or services for leisure and recreation activities	
5	Case Management	Assistance with locating and securing benefits and program services. Also called service coordination	
6	Transition Support	Assistance moving from school to work	
7	Social Skills Training	Social skills training and specialized behavior management services	
8	Financial Assistance	Payments from government agencies directly to the individual	
9	Life Skills Training	Education and training in basic life skills	
10	Community Inclusion	Assistance to access /participate in community activities	
11	Assessment	Specialized evaluations and assessments	
12	On the Job Support	Assistance in job from support provider agency	
13	Mental Health Care	Direct mental health care and/or funding or subsidy	
14	Housing Assistance	Subsidies, financing, modification, locator services	
15	In-home Support	Independent living support or support in the family home	
16	Family Financial Subsidy	Direct funds to family for purchase of necessary service or equipment	

Relationship Between Need and Age

As expected, the priority needs for support vary according to one's stage in life. Comprehensive educational services are critical for children and youth whereas housing and job support become more of a priority as one enters adulthood.

Figure 7 illustrates the similarities and differences between age and the priority individuals and families placed on each of the services and supports that were listed in the survey. As previously discussed, respondents identified service coordination, community inclusion services, medical and health care, and recreation services as important supports across all three age groupings.

School-

"One of the things I feel strongly about is that... school is about 20% or less of my son's waking hours, and he really needs school to teach him <u>all</u> the time."

Focus Group Parent

Survey Facts

- Of the 791 survey respondents, **636 did not** have mental retardation and had their disability diagnosed prior to 22 years of age.
- Of these 636 respondents, 455 were children and youth birth through 18 years of age and 181 were adults 19 years of age and older.
- Of the 455 children in the survey sample, over 70% were under 10 years of age, with a mean age of 9.9 years.
- The mean age for respondents over 18 years of age was 34.6 years.
- Of the 455 children in the sample, 62.9% (n = 286) could be categorized as being on the autism spectrum.
- For the sub-sample of 241 individuals who likely have a developmental disability, 77% (n = 186) were children and youth birth through 18 years of age and 23% (n = 55) were adults 19 years or older.

Figure 7. Illustration of priority supports by age range for entire survey sample.

← AGE RANGE →		
CHILDHOOD	TRANSITION	ADULTHOOD
Re	ecreation & Leisure Supp	ort
	Medical and Health Care	
	Service Coordination	
Co	ommunity Inclusion Supp	ort
Education		
Assessment		Assessment
Social Skills & Behavio	r Management Training	
Life Skills	Training	
	Transition Support	
	Transporta	tion Support
	Job Placement & Training	
	Financial Assistance to Individual	
Family Counseling &		
Training		
		Assistive Tech
		Personal Assistant

General Conclusions About Expressed Service and Support Needs

developmental disability other than mental retardation.

The combined results of the survey and themes generated by the focus groups lead to the following general conclusions regarding the expressed needs for services and supports for persons with a

- 1. The configuration of needed supports is highly individualized. Although the majority of persons with a developmental disability may not have an existing need for any given service, in every single instance there were some individuals who had a substantial need. Consequently, a menu of services and supports needs to be made available to allow each person to custom-tailor their support plan.
- 2. A comprehensive educational plan provided by the school is the most critical need for children. Moreover, schools do not typically provide the other priority services and supports identified by families, such as respite care, family education, or service coordination, even when the child is designated as needing special education.
- 3. Individuals with disabilities and their families see service coordination as a vital service to assure effective planning and access to supports. Yet, cross program or cross agency service coordination is noticeably absent from the current

- service system for both children and adults.
- 4. The findings and conclusions of the IFSS Committee are very similar to findings of other legislated and nonmandated committees, workgroups, and contracted studies. These include several studies completed in the late 1980's (e.g., Human Service Research Institute, 1987), the Long-Term Care Committee, the Olmstead Planning Workgroup, Connecticut Family Support Council, OSEP Self-Assessment Committee, just to mention a few. Despite the fact that the gaps in service have been studied again and again, the need to support Connecticut citizens with disabilities continues to exist.

Current Access to Services

The second major question addressed by the IFSS committee focused on the degree to which individuals with developmental disabilities and their families are currently able to access and receive needed services. In general, the number of people who actually receive any given service, with the exception of education, is almost always significantly lower than the number who express a need for a particular service.

While this relationship between need and access is evident across age groups, the analysis of survey results suggest that services to families of adults with disabilities are less well developed.

Moreover, family support services in general appear to be the least effective as reported by survey respondents.

Information obtained from the survey and focus groups also indicates that most individuals and families (about 80%) are currently using personal funds to pay for many services. This is particularly true for medical and mental health care and special transportation. Approximately 1

out of every 3 respondents indicated that families are paying for supplemental educational services (e.g., special tutoring, speech and occupational therapy, summer programs).

Comments from both survey respondents and focus group participants strongly suggest that in Connecticut people with developmental disabilities are not afforded the opportunity to access the supports they need to live full productive lives in the community. These data further suggest that access to services is often a function of the ability and willingness of a family to use *personal funds* to pay for the service. Interestingly, many individuals confirm that the bureaucratic maze is frustrating and inefficient and believe that the complexity of the system has been established to prevent access to needed services.

Consumer and Family Ideas on Changing the System

Individuals with developmental disabilities and their families were asked to recommend changes to the current

system that would allow them to access and receive the services and supports that they needed the most. Many of their ideas focused on the major themes outlined in Figure 8.

Figure 8. Consumer and family recommendations for system change.

Figure 6. Consumer and family recommendations for system change.			
SYSTEM COMPONENT	RECOMMENDATIONS FOR SYSTEMS CHANGE FROM CONSUMERS & FAMILIES		
General	 Replicate the "Birth to Three" model – with its focus on individualization, inhome support, service coordination, family focus, and entitlement. We need a working transportation system regulated at the state level. The personal care assistant (PCA) needs major improvements. Must develop good assisted living, in-home supports, and respite services for people with DD and their families. 		
Eligibility	Use functional assessment and not diagnosis and age to determine eligibility for service.		
Access	 Establish a central entry point – regardless of diagnosis, that can also provide information. Make access local. Provide a plan or referral for everyone who enters the system. 		
Coordination & Planning	 Case management/service coordination and individualized planning must be key components in any revised system. Service planning must be comprehensive and not focused on just vocational needs. Funding and ability to pay should be part of the planning process. Plans should develop from a menu of options. 		
Quality	 Cross agency communication and information sharing is needed along with an integrated database. System must be easy to navigate. System should have an appeal process for eligibility decisions. Agency and provider staff should assume a customer service mentality - respectful and responsive. 		
Funding	 System should promote flexible funding, flexible income caps, and sliding scales based on individual and family ability to contribute. Include vouchers and debit cards to pay for services and specialized equipment maintenance. 		
Inclusion	 Assure major involvement of individuals with DD and families in any planning around revision to the system. Establish leadership roles for persons with disabilities. 		
Health Care	 Must improve the knowledge and understanding of disabilities by medical providers. Establish a "HUSKY" type plan for adults to improve access and coverage. 		